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Nick Heuchan, center, with his Scout leaders

SCOUTING MADE ACCESSIBLE

For elementary aged children all over the country scouting is a rite of passage, boys and girls dream of earning badges and making lifelong friends. This dream, however, is not always possible for children with disabilities. Thanks to leaders like Rich Gambrill of Dundalk, Maryland and Lisa Rosenfeld of Staten Island, New York more children with challenges are living their scouting dreams.

A father of a special needs child himself, Richard Gambrill wanted a troop where his child and others could belong, fully participate at their own paces and make friends. So in 2008 he formed Troop 117, which lifts the Eagle Scout restriction of age 18 and allows boys to achieve the distinction by earning all of the same merit badges as typical scouts without the age constraint.

Nicholas Heuchan, CLN3, a proud member of Gambrill's Troop 117, achieved the coveted Eagle Scout rank this past March even before he turned 18. Nicholas is the first in his troop to earn the honor. Through his journey to get there he acquired the requisite merit badges, including his favorites, cooking

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and coin collecting, and the difficult cycling merit badge that took three years to complete. For his Eagle Scout Service Project, Nicholas recruited volunteers to construct four unique handicap accessible picnic tables for his school, the Maryland School for the Blind.

Lisa Rosenfeld, a dedicated and inspiring teacher at Staten Island PS37, not only works with students with a diverse range of developmental delays in the classroom but she is also the leader of a unique Girl Scout Troop for girls with disabilities. In 2001 she started Troop 5312, which has grown in 14 years from six to over 50 girls.

Michelle and Lauren Surrey, CLN3, are Girl Scouts in Lisa's troop who earn patches, bond with one another and other friends, and enjoy the opportunity to assist and be assisted by their peers. Michelle and Lauren enjoy craft projects, outings and trips, and Miss Manners practice. Their leader, Lisa, works hard to involve the girls in as many typical scouting activities as possible while still keeping in mind their comfort and the comfort of their parents. She insists on never holding her troop back, she always encourages them to move to the front of every crowd and fights for their right to enjoy their freedom.

Scouting, like many other quality of life activities, is a vital part of making sure children are able to do what children do best, learn and play. Thanks to the generous leadership of Rich Gambrill and Lisa Rosenfeld, Nicholas Heuchan and Michelle and Lauren Surrey are enjoying incredible and rewarding experiences of scouting.

Lisa Rosenfeld completes craft projects with Lauren Surrey

“The girls bond with one another and enjoy the opportunity to assist and be assisted by their peers.”

NEWS FROM OUR SUPPORTERS

CAITLIN ROSE EYESHADOW IS HERE!

Makeup Geek donates 100% of the profits from their Caitlin Rose Eyeshadow to support research and the families affected by Batten Disease. Marlena, co-founder of MakeUp Geek, is a close family friend of the Allio's and considers Caitlin and her family to be a part of her own.

Caitlin Rose Eyeshadow can be purchased at:
<http://bit.ly/1FGUetU>



FROIOS ROLL THE DICE FOR RESEARCH

Gregg and Paula Froio and dozens of volunteers hosted the 5th annual Road to a Cure Monte Carlo Night in Berlin, New Jersey on February 28th. More than 350 people attended the dinner and evening of entertainment, which is the 16th year the Froio family has organized this event. It honors their daughter Melissa, who was diagnosed with late infantile Batten disease in 1999. The Froio's formed the Melissa Froio Foundation to raise money for Batten disease research. After this year's event the Froio family donated a generous \$11,000 to BDSRA.



PERCUSSION PALOOZA DRUMS UP FUNDS

This May the Hoover Middle School in Waterloo, Iowa held a Percussion Palooza. This incredible event included a percussion concert, dessert bar, gallery walk, petting zoo, and an electronic drum set for attendees to try. The school donated \$1,450 to BDSRA in honor of Nick Wellner and Jax Engstrom.



NEWS FROM OUR SUPPORTERS

NORD HONORS TONY FERRANDINO

BDSRA would like to congratulate board member Tony Ferrandino who was named one of the National Organization for Rare Disorder's 2015 Portrait of Courage Honorees. Each year NORD chooses 10 patients and caregivers that highlight people affected by rare disease and their stories of courage, determination, and perseverance in the face of great odds. We are incredibly honored to have Tony on the board and thank him for his commitment to the families and organization.



HEIN FAMILY TRIVIA NIGHT

On February 20th, the Hein family held their 12th annual Trivia Night to raise funds for Batten disease research. Even though there was freezing rain that evening, they had over 150 friends attend to support their efforts toward finding a cure. \$5,700 was donated to BDSRA earmarked for research. They plan to hold this event again in 2016.



KATHERINE B. SIMS, MD, ENDOWED CHAIR AT MASSACHUSETTS GENERAL HOSPITAL

On May 7, 2015, the new Katherine B. Sims, MD, Endowed Chair in Neurogenetics was celebrated along with the many years of service Dr. Sims has provided to the rare disease community. She was the founding member of the Massachusetts General Hospital Neurogenetics DNA Diagnostic Lab in 1994. Since that time, she has helped unravel the mystery of over 30 rare disease, including Batten disease where she is the leader of the Batten Center of Excellence.

Shown below are Dr. Sims with the new holder of the Sims Chair, Dr. Katherine Swoboda, who will carry on the fine work of the Lab. Dr. Swoboda is a national expert in newborn screening and was a primary speaker at this year's BDSRA annual conference.

Dr. Sims will continue her work at MGH as Master Clinician, continuing her legacy of caring for families who need her most. Thank you for your years of service and scientific discovery, Dr. Sims!



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join the BDSRA
conversation online!



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ROCHESTER CENTER OF EXCELLENCE RESEARCHERS PRESENT WORKSHOP AT FOOD AND DRUG ADMINISTRATION

Dr. Jon Mink and Dr. Heather Adams recently participated in a two-day workshop (April 16-17, 2015) at the U.S. Food and Drug Administration, “Public Workshop on Assessment of Neurocognitive Outcomes in Inborn Errors of Metabolism and Advancing the Development of Pediatric Therapeutics (ADEPT)”. The first day of the workshop focused on assessing neurocognition, as an efficacy outcome, in clinical trials for individuals with disorders such as Batten disease. The second day of the workshop focused general issues and challenges related to assessment of neurocognition in the developing child.

Dr. Mink presented two talks on Day 1: “Clinician Perspective” (focusing on clinician perspectives related to efficacy clinical trials), and “Batten Clinical Rating Scale”, an overview of the Unified Batten Disease Rating Scale. Dr. Adams also presented a talk on Day 1 of the workshop, “Use of remote technology to expand the reach of clinical research”. This talk reviewed the URBC’s work to evaluate children with Batten disease through remote, live video visits.

Dr. Adams also served on the planning committee for the Day 2 workshop and co-chaired one of the Day 2 workshop sessions, “Tools and strategies in the evaluation of neurocognitive and behavioral outcomes in products used to treat children”. Full details of the workshop, including all slide presentations, are publicly available at the FDA website: www.fda.gov/Drugs/NewsEvents/ucm434954.htm

A transcript of the meeting is forthcoming and will also be made available to the public on the FDA website.



BDSRA IS ALL ABOUT FAMILIES CONNECTING WITH EACH OTHER

Help us update the BDSRA family directory.

If you would like to be included, please send your name, address, contact information and affected person’s name and NCL type to tkirby@bdsra.org.

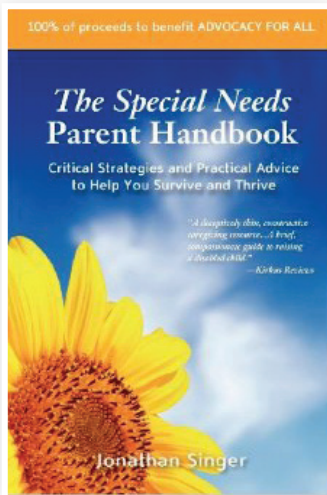
This information is for the directory only. BDSRA does not sell or share the directory with outside companies or organizations.



the BDSRA BOOKSHELF



Adult Book Selection



“From Emotions to Advocacy: The Special Education Survival Guide”

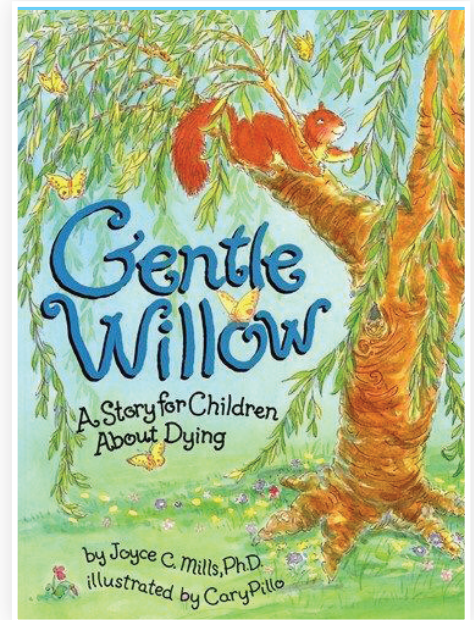
by Peter Wright, Esq. and Pam Wright. 2nd Edition.

This book provides parents and caregivers with practical advice for advocating for their child in the school system. It includes information about developing a master plan for your child’s education, strategies for resolving conflict with school personnel and tips for writing good IEP (Individualized Education Plan) goals and objectives.

The book also provides an overview and detailed information about the IDEA 2004 (The Individuals with Disabilities Education Act of 2004) including:

- Findings and purposes of the IDEA Definitions in the IDEA
- Extended school year (ESY), child find, least restrictive environment (LRE), private placements, statewide assessments
- Requirements for identifying children with specific learning disabilities - Discrepancy Formulas and Response to Intervention (RTI)
- Evaluations, eligibility, IEPs, and placement
- Prior written notice, procedural safeguards, mediation, due process hearings, appeals, discipline, and age of majority
- Section 504 of the Rehabilitation Act

Children’s Book Selection



“Gentle Willow: A Story for Children About Dying” by Joyce C. Mills

Written for children who are elementary school age, who may not survive their illness or for the children who know them. This book selection is a tender and touching tale that helps address feelings of disbelief, anger, and sadness, along with love and compassion. Characters Amanda and Little Tree discover that their friend Gentle Willow isn’t feeling well. (Copyright 2003).



*in loving
memory*

MABEL LARSON, daughter of
Ramee Larson, Clinton IL
Born: 7-16-10 | Died: 5-29-15
(Unknown)

MARY MARTHA "EMMY" CERNIGLIA,
daughter of Ted and Suellen Cerniglia,
Fruitport MI
Born: 10-14-86 | Died: 5-16-15
CLN3 (Juvenile)

WILLIAM FORREST BRADDOCK, son of
Jason and Braley Braddock, Bryant AR
Born: 5-22-12 | Died: 5-10-15
CLN2 (Late Infantile)

LEAH FITZGERALD, daughter of
Donna Fitzgerald, Elgin SC
Born: 6-8-84 | Died: 5-5-15
CLN3 (Juvenile)

COLTON USTRUCK, son of Bill and
Melissa Ustruck, West Allis WI
Died: 4-17-15
CLN2 (Late Infantile)

REBECCA "BECCA" COLLINS, daughter
of Mike and Dawn Collins, Mokena IL
Born: 6-12-99 | Died: 4-14-15
CLN1 (Infantile)

KATELYN PAULING, daughter of Jeremy
and Kristy Pauling, Montevideo MN
Born: 9-19-06 | Died: 3-20-15
CLN2 (Late Infantile)

AMIAYA JONES- CASSIDY, daughter of
Tiara Jones- Cassidy, Malvern AR
Born: 7-16-06 | Died: 3-15-15
CLN2 (Late Infantile)

MARY PAYTON VIGIL, daughter of Nikki
and Joe Vigil, Mandeville LA
Born: 5-28-03 | Died: 2-25-15
CLN2 (Late Infantile)

BRITTNI BLANKENSHIP, daughter of
Tami Vas, Carpentersville IL
Born: 9-16-90 | Died: 2-2-15
CLN3 (Juvenile)

KATIE KEEPING, daughter of Richard
and Donna Keeping, Cambridge,
Ontario, Canada
Born: 2-15-06 | Died: 1-25-15
CLN2 (Late Infantile)

SETH ALAN LEE DUNFORD, grandson of
Crystal Freeman, Nevada OH
Born: 9-6-08 | Died: 1-19-15
CLN2 (Late Infantile)

MARA ELISE NICK, daughter of Robert
and Alice Nick, Leander TX
Born: 10-9-91 | Died: 12-28-14
CLN3 (Juvenile)

BRYLEE GRACE HOLMES, daughter
of Joseph and Stacey Holmes,
Decaturville TN
Born: 3-6-09 | Died: 12-16-14
CLN2 (Late Infantile)

ASHER NIKOLAJEVs, son of Victor
Nikolajevs, Berlin Heights OH and
Leisa Oakes, Milan OH
Born: 3-11-97 | Died: 12-20-14
CLN1 (Infantile)

COURTNEY JOHNSON, daughter of Tim
and Denise Johnson, Georgetown OH
Born: 3-25-98 | Died: 11-5-14
CLN3 (Juvenile)

BDSRA takes great care to memorialize those individuals who have passed away from Batten disease. If a person is omitted from this page, it is because BDSRA was not notified of the death, did not have permission to publish, or did not have confirmed information.

FIRST QUARTER DONOR GIFTS

(Gifts given January 1, 2015 through
May 15, 2015)

The Batten Disease Support and Research Association has been remembered many times in the past four months by families and friends affected by Batten disease. Thank you for your generous contributions. This support for the vital mission of research and services for families is crucial to finding a cure. We are also grateful to those supporters who have participated in events and volunteered their time to advance our efforts for Batten disease research and family services.

IN HONOR OF:

JOVAN ALLEN
Kimberly Reason

ANNIE ALLIO
Imelda Kuykendall
Sean Maddison

JOSEPH ALLIO
Catherine Allio

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GARRETT COYNE
Garrett the Grand – Batten Fighter

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**CAROLYN WILHELM and in honor of
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**Donations from these events
were made to BDSRA
through May 15, 2015:**

Catie and Annie's Cops
*In memory of Catie Allio and in honor of
Annie Allio*

Casino Night
In memory of Melissa Froio

Comedy Night
In honor of Mason Smerdel

Family Garage Sale
In memory of Ethan Davies

Heart of America Chapter Trivia Night
In memory of Austin Hein

Percussion Palooza
*In honor of Jaxton Engstrom
and Nicholas Wellner*

Run for Broxton
In memory of Broxton Taylor

Run the Creek
In honor of Brandon and Jeremy Hawkins

Sofia's Journey (Find A Cure)
In memory of Sophia Grace Crawford

T-shirt Sale
In honor of Sam Engman

T-Shirt Sale Coordinated by Kaitlyn Carbrey

**Approximately \$47,700 was donated to
BDSRA for research and services.**

*Please direct any questions or concerns
regarding this list to Noreen Murphy at
nmurphy@bdsra.org or (800) 448-4570,
ext. 14. Thank you for your continued support.*